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Abstract

Research on childhood epilepsy has predominantly used quantitative methodologies to examine the impact of epilepsy on young people and their families. These studies generally give a negative picture of the condition which is at odds with a strengths-based social work perspective and provide little understanding of young people's experiences of living with epilepsy. A systematic review of qualitative studies that explored young people's perspectives was conducted. Inclusion criteria included: young people diagnosed with epilepsy, ages 13 to 18 years old; qualitative data collection methods; studies published in English-language peer-reviewed journals and grey literature. Of 501 abstracts identified, 52 full-texts were reviewed with 17 studies being included for final analysis. The emergent themes were: seizures and medications; relationships, issues and concerns involving their families, peers, and schools; young people's reactions to epilepsy. Issues presented by young people are essential in improving practice and developing services, as it highlight areas for potential social work interventions. In addition, it is essential to adopt a strengths perspective when considering these findings and implications for hospital social work, as young people's experiences were not always negative.

Keywords: Adolescents; epilepsy; systematic review; qualitative

INTRODUCTION

Epilepsy is one of the most common neurological disorders in children and young people, characterized by its chronicity and unpredictability of symptom exacerbations (Chan et al., 2010; Guerrini, 2006). Young people with epilepsy not only have to cope with the challenges of living with a chronic seizure condition (e.g., uncertainty of seizure occurrence, treatment adherence), but also have to adjust to normative tasks associated with adolescence such as developing peer relationships (Christie & Viner, 2005; Patterson & McCubbin, 1987). Managing additional

demands simultaneously is likely to be more stressful for young people and their families compared to peers without a chronic medical condition. In turn, their ability to cope with these multiple demands is likely to influence young people's adaptation.

Most research examining how epilepsy affects children and adolescents has used quantitative methods (McEwan, Espie, & Metcalfe, 2004a). Several systematic reviews concluded that epilepsy was associated with higher levels of psychiatric diagnosis, externalizing and internalizing problems, lower health-related quality of life, social competence and poorer academic achievements, compared to their peers (Rantanen, Eriksson, & Nieminen, 2012; Reilly & Neville, 2011; Rodenburg, Meijer, Dekovic, & Aldenkamp, 2005; Stevanovic, Tadic, & Novakovic, 2011). These studies generally give a negative picture of the condition which is at odds with a strengths-based social work perspective and provide little or no understanding of young people's experiences of living with epilepsy. As the likelihood of positive adaptation increases when interventions are based on issues patients deem as important, it is crucial for social workers to understand young people's perspectives in order to be more effective when supporting them and their families.

A review of studies conducted between 1982 and 2003 found only six that used qualitative methods and only one of these met the reviews quality criteria for inclusion (McEwan et al., 2004a). It is therefore quite timely to undertake an updated review to provide hospital social workers with a broader understanding of young people's perspectives on living with epilepsy, their psychosocial needs and their sources of support. This may facilitate the development of interventions and practice guidelines that are patient-centered, and for resources to be directed toward addressing young people's key concerns.

A scoping review was conducted with the objective of providing an overview of qualitative studies that explored young persons' perspectives of living with epilepsy. Taking into consideration the influence of developmental changes on young people's perceptions and experiences, the present review is limited to studies involving young people aged 13 to 18. The aims are three-fold. First, to ascertain the extent to which young people's perspectives were examined through the use of qualitative and mixed methods research designs. Second, to summarize the research findings and draw out their implications for social work practice. Third, to identify gaps in the existing literature and highlight potential areas for future research.

METHOD

This study followed the five-phase framework for conducting scoping reviews by Arksey and O'Malley (2005) as follows:

(i) *Identifying the research question*: What are young people's perspectives of living with epilepsy?

(ii) *Identifying Relevant Studies*: An electronic search for studies that used both qualitative data collection and analysis methods was conducted. The search terms, which consisted of medical subject headings (MeSH), subject headings and text words, for young people with epilepsy, qualitative study design and data collection methods were combined to identify the relevant articles. Electronic searches were conducted for all material available on the following databases from their inception to August 2015: The Cochrane Library, MEDLINE, PsycINFO, Embase, Cumulative Index to Nursing and Allied Health Literature (CINAHL). Articles from peer-reviewed journals and grey literature were included. References of selected articles were also examined.

(iii) *Study Selection*: Studies were included if they involved young people aged 13 to 18 years old. Those with a wider age range were included only if the data for the target group could be extracted separately. Only studies that used both qualitative data collection and analysis methods to explore young people's perspectives were included. Studies that involved young people solely for the purpose of evaluating treatment were excluded.

(iv) *Charting the Data*: The data extracted were general study characteristics, such as year of publication, and location; participant information, such as sample size, and age; aims of the study; data collection methods; findings.

(v) *Collating, Summarizing and Reporting the Results*: The findings was organized thematically according to seizures and medications; relationships, issues and concerns involving the family, peer, and school sub-systems; young people's reactions to living with epilepsy.

RESULTS

Of 501 citations identified, 52 full-text articles were retrieved and reviewed; 35 were subsequently excluded as they did not meet the inclusion criteria (refer to Figure 1). The summary of the remaining 17 articles is presented in Table 1.

Seizures and Medications

Several studies explored young people's understanding and knowledge of epilepsy, and their descriptions of the signs and symptoms of an impending seizure (also known as auras). These included a general sense of discomfort, light stimuli such as flashing lights, and when they were feeling tired (Galletti, Rinna, & Acquafondata, 1998) as well as the loss of control over bodies (Eklund & Sivberg, 2003; Galletti et al., 1998) and in some cases physical injuries were sustained during their seizures (Eklund & Sivberg, 2003; McEwan, Espie, Metcalfe, Brodie, & Wilson, 2004b). Young people not only experienced fear that related to injuries, they were also

concerned about potential damage to their brains as a result of seizures (Ryan & Raisenen, 2012). Most of the young people experienced fatigue after seizures affecting their concentration or return to activities (Elliott, Lach, & Smith, 2005; Galletti et al., 1998; Lewis & Parsons, 2008). Self-management behaviors, such as getting sufficient sleep, massaging their heads and distracting themselves, were perceived to be helpful in preventing seizures (Galletti et al., 1998; McEwan et al., 2004b).

While most young people either believed or hoped that they would grow out of epilepsy, some feared that their condition would worsen (Eklund & Sivberg, 2003; Lewis & Parsons, 2008; McEwan et al., 2004b). Others believed that whether or not they remained seizure free depended on luck (McEwan et al., 2004b). Several wondered whether their medical condition would have a negative impact on their future, being particularly concerned about being unable to drive, going out with friends, safety issues if they lived alone, limited career options and having children (Lewis & Parsons, 2008; Manski & Dennis, 2014; McEwan et al., 2004b; Swarztrauber, Dewar, & Engel Jr, 2003).

Young people's knowledge of anti-epileptic medication (AED), their feelings and perceptions towards taking medication, and adherence issues were explored in several studies. Young people obtained information regarding their medication mainly from their parents and/or healthcare professionals, and their knowledge and understanding of the purpose of AED varied (Lewis & Parsons, 2008; Manski & Dennis, 2014; Swarztrauber et al., 2003). Several felt that their questions about their medications and illness were not adequately addressed (McEwan et al., 2004b; McNelis, Buelow, Myers, & Johnson, 2007; Swarztrauber et al., 2003). Others also expressed their frustrations with the lack of information and relied on the internet instead (Swarztrauber et al., 2003). Young people wanted to be as well informed their parents but

medical terminology was a barrier to their participation (Beresford & Sloper, 2003; McNelis et al., 2007; Wilde & Haslam, 1996).

Their feelings about taking AED were mixed. While some accepted that they needed AED, most disliked and felt tired of taking medication and accompanying side effects, perceiving it a burden. (Eklund & Sivberg, 2003; Galletti et al., 1998; Lewis & Parsons, 2008). They also perceived medications as a representation of their medical condition: not only was it a physical reminder, it was marked their difference from peers (Eklund & Sivberg, 2003; Galletti et al., 1998; McEwan et al., 2004b).

Adherence to AED medication was also highlighted in various studies. Some related their concerns about forgetting their medication without reminders from parents (Swarztrauber et al., 2003), others reported frustration with parents' 'over-vigilance' (Elliott et al., 2005; McEwan et al., 2004b). Frustration also stemmed from disruptions to participation in social activities in order to take their medication. Older adolescents concerned that lifestyle choices, such as experimenting with alcohol, may affect the efficacy of their AED (McEwan et al., 2004b) and young women reported difficulties in identifying the appropriate combination of oral contraceptives and AED (Manski & Dennis, 2014). With the exception of Carter et al. (2012) and Mushi et al. (2011) there was limited information on cultural differences regarding treatment practices. Perceptions of the causes of epilepsy and belief in traditional practices and treatment methods, were some reasons for the under-utilization of AED.

Within the Family

Young people acknowledged the support of their parents and siblings, and maintained good relationships with them (Eklund & Sivberg, 2003; McEwan et al., 2004b; Mushi et al., 2011; Wilde & Haslam, 1996). However, these relationships were occasionally challenged when the

demands of illness management conflicted with restrictions on social and recreational activities, and the loss of autonomy and independence. Wilde and Haslam (1996) concluded that, while parents were concerned and protective of their children, they generally allowed them independence where possible. Parental concerns were usually about the higher risk of injury or death should a seizure occur, such as swimming and rock climbing (Eklund & Sivberg, 2003; Elliott et al., 2005; Lewis & Parsons, 2008), exacerbated by a past history of physical injuries (Wilde & Haslam, 1996). However, some parents became less protective when they gained more knowledge about epilepsy and its associated risks (McEwan et al., 2004b), and when they gained confidence in their children's independence (MacLeod, 2009). Notably, restrictions were sometimes self-imposed by the young people themselves to ensure their own safety (McEwan et al., 2004b). Some parents were described as hyper-vigilant and excessive worriers. For instance, some young people related that they were unable to lock their bedroom doors and could not be alone (McEwan et al., 2004b). They perceived this as a loss of autonomy and privacy, and reported anger over such parental control (Elliott et al., 2005; Galletti et al., 1998).

Among Peers and Friends

An issue that was discussed across most studies was regarding disclosure of their medical condition to peers and friends. Disclosure was unintended for some young people. Often, friends knew about young people's medical condition only after witnessing a seizure (Wilde & Haslam, 1996). For those who chose to disclose, the decision was dependent on several factors such as the relationship with their peers, frequency of their seizures and safety reasons (Lewis & Parsons, 2008; Wilde & Haslam, 1996). Furthermore, some young people felt that it was difficult to disclose to their friends and teachers (Eklund & Sivberg, 2003). Some, felt embarrassed about their medical condition (McEwan et al., 2004b) and others feared that their peers would laugh at

them, label them as 'stupid', bully or would reject them (MacLeod, 2009; McEwan et al., 2004b).

Other important issues were the reactions of their peers to their medical condition. Young people generally disliked their peers' reactions after they witnessed a seizure; crying or avoidance often made them feel bad about themselves (McEwan et al., 2004b). They postulated that their peers were afraid of seizures due society's ignorance about epilepsy, which in turn contributed to prejudice and discrimination (Eklund & Sivberg, 2003; McEwan et al., 2004b; Wilde & Haslam, 1996). While some described their relationship with peers and friends as "*normal*" (Galletti et al., 1998), others described being rejected, bullied, teased and labelled by peers (Elliott et al., 2005; Hum, Smith, Lach, & Elliott, 2010; Lewis & Parsons, 2008; MacLeod, 2009; McEwan et al., 2004b; McNelis et al., 2007; Wilde & Haslam, 1996). On occasions, they were portrayed by their peers as "*different*", were excluded from social activities; some reported a lack of close friendships.

Nevertheless, not every young person's experiences was negative. Young people also described their friendships as satisfying and friends were supportive (Elliott et al., 2005; Hum et al., 2010). On occasions, friends also protected the young people from being teased by others and these behaviors provided them with a sense of loyalty and acceptance (MacLeod, 2009). Sometimes, friends were interested in finding out more about epilepsy and knowledge of what to do during a seizure (Elliott et al., 2005; McEwan et al., 2004b). In response, young people often assumed the responsibility to educate their peers and friends about seizures, and in turn this led to greater acceptance and reduction of teasing (Elliott et al., 2005; Wilde & Haslam, 1996). Some commented that information sheets about epilepsy made it easier to educate their peers about their medical condition (McEwan et al., 2004b).

School and Education

Young people encountered difficulties in managing their school engagements due to the effects of seizures on their cognitive functioning. Some described that they had poorer memory and had to make great efforts in order to concentrate during classes and to remember what was taught (Elliott et al., 2005). Additionally, young people often experienced fatigue after seizures and this also affected their ability to concentrate. Others related that they missed classes due to seizures or medical appointments (MacLeod, 2009; McEwan et al., 2004b; Swarztrauber et al., 2003). These factors pose challenges to young people's education and would need to be addressed in order to ensure that their learning is not unnecessarily compromised.

Young people considered that some teachers over-reacted to seizures and that others were unsupportive (McEwan et al., 2004b). On occasions, young people felt discriminated against by teachers who restricted their participation in school activities (Eklund & Sivberg, 2003; Galletti et al., 1998; McEwan et al., 2004b). Such restrictions are likely to add to feelings of exclusion that young people may have already experienced. However, others reported that their teachers were supportive and understanding (Elliott et al., 2005; Lewis & Parsons, 2008; McEwan et al., 2004b). One possible explanation for the differences in teachers' responses is the level of training or knowledge regarding the capacities of young people with chronic illnesses. These variations highlight the importance of supporting educators, such as addressing their concerns in meeting the needs of young people with chronic medical conditions. Minimizing inaccurate appraisals of young people's ability to participate in school activities would provide an environment that is more supportive and inclusive.

Young People's Reactions to Living with Epilepsy

Feelings of anger, sadness, and frustrations about having epilepsy were often reported (Elliott et al., 2005; McEwan et al., 2004b; Wilde & Haslam, 1996). Young people attributed these feelings to the occurrence of seizures, the constant need to take medication, and restricted activities. Reduced levels of participation also made them feel different from their friends, and some felt that their peers could achieve more than them (Galletti et al., 1998; McEwan et al., 2004b; McNelis et al., 2007). They also reported feelings of loneliness, embarrassment, self-consciousness, and self-pity. These feelings were often expressed during discussions of the unpredictability of seizures, loss of control of their bodies, and having seizures in public (Elliott et al., 2005; Galletti et al., 1998; McEwan et al., 2004b; Wilde & Haslam, 1996). Fears about living with epilepsy and having seizures, injury and death were also expressed (Galletti et al., 1998; McEwan et al., 2004b; Ryan & Raisanen, 2012; Wilde & Haslam, 1996).

However, despite these challenges and feelings, young people also expressed that they were no different from others except for their seizures (MacLeod, 2009). They have also demonstrated effective coping strategies to resolve challenges such as academic challenges and bullying (Elliott et al., 2005; MacLeod, 2009). Several also perceived that they had learned to live with seizures, coped well and would not have changed their lives (McEwan et al., 2004b).

DISCUSSION

This review of qualitative studies, which explored the perspectives of young people with epilepsy, identified issues that young people rather than social workers and other professional believed important; they also represent potential areas for social work interventions.

Young people with epilepsy have to manage normative tasks associated with adolescence and illness demands. For instance, having to be aware of possible interaction effects of alcohol or oral contraceptives on their AED (Manski & Dennis, 2014; McEwan et al., 2004b). This

underscores the importance in social work assessments of identifying the young people's individual concerns. Their narratives also highlight the significance of young people's interaction with their peers. Their concerns about disclosure were often about negative reactions from their friends and peers. Interventions aimed at supporting young people through the process of disclosure should address these concerns and help young people to harness their existing support (i.e., close friends).

There are limitations in the literature reviewed here. Most studies were conducted in the United Kingdom and North America, and there is limited information on cultural differences relating to young people's experiences. Research with adults has described the influence of culture on people's beliefs about illness and treatments and social functioning (Guo et al., 2012; Ismail, Wright, Rhodes, & Small, 2005; Jacoby et al., 2008). For instance, Guo et al. (2012) and Jacoby et al. (2008) found that that epilepsy was perceived to have a major impact on the marriage prospects of adults with epilepsy in Vietnam and China. This was attributed to the belief that epilepsy can be inherited and thus could be passed onto their offspring. Taking into consideration the differing effects that society on living with long-term conditions, there is a need to extend research on cultural and economic influences on young people's well-being.

The percentage of young people with both epilepsy and learning disabilities is between 31% and 41% (de Boer, Mula, & Sander, 2008). However, only one study reviewed involved young people who had learning disabilities (Ryan & Raisanen, 2012), greatly reducing the opportunities for understanding their needs and allowing for their views to be expressed.

The studies focused primarily on young people's descriptions of living with epilepsy and there is limited information on family processes such as communication and cohesion and its effects on young people. Parents are often involved in the management of illness demands, for

instance having primary responsibilities for decision-making relating to treatment. Treatment adherence is also dependent on parents' commitment in ensuring that their children attend medical appointments and take their medications as prescribed. Evidence suggests that family functioning is one of the factors that influence treatment adherence (Mitchell, Scheier, & Baker, 2000), and that adherence is not solely dependent on the young person. In addition, the lack of clarity of roles and responsibilities, and differing expectations with regard to the management of a young person's medical treatment, is also likely to result in poorer levels of adherence.

Although illness-related management may be challenging, families often demonstrate resilience and are successful in managing these demands. Future research could focus on family processes that promote resilience and strengths (Rolland & Walsh, 2006). While young people experienced challenges and negative experiences, they also experienced support and had positive encounters as well. This has implications for strengths-based social work interventions for young people living with epilepsy and/or other forms of chronic illnesses. Instead of focusing on alleviating problems and overcoming deficits, interventions can be directed at harnessing existing individual and family strengths to meet the challenges faced.

Findings from the present review were broadly similar to reviews that examined the experiences of young people with other chronic illnesses such as cystic fibrosis, renal failure and cancer (Jamieson et al., 2014; Tjaden, Tong, Henning, Groothoff, & Craig, 2012; Woodgate, 2000). Common experiences included young people's positive and negative evaluations of their current circumstances, abilities, and/or participation through comparisons with their past or with reference to their peers; feelings of isolation due to exclusion by peers, loss of autonomy, and restrictions; issues related to treatment; support from family and friends; and coping strategies (Jamieson et al., 2014; Tjaden et al., 2012; Woodgate, 2000). Similarly, support from family and

friends in the form of comfort, reassurance and encouragement were appreciated and valued by young people. The commonality of issues supports the use of a non-categorical approach to childhood chronic illness (Stein & Jessop, 1982): regardless of medical condition, young people living with chronic illnesses experience common stressors and challenges that may negatively affect their psychological and social functioning.

Although their experiences can be considered similar, the extent to which these issues affect young people differ, and this is likely due to differences in the onset, course and outcome of the illnesses. For instance, treatment demands placed on young people with epilepsy (e.g., taking AED) are lower than that of those with cystic fibrosis (e.g., medication, physical therapy and lung clearance) or kidney diseases (e.g., dialysis). In addition, differences in physical appearance, such as short stature and finger clubbing, among young people with cystic fibrosis (Jamieson et al., 2014), and having to be connected to a catheter for some young people with kidney disease (Tjaden et al., 2012), pose different sets of challenges that young people with epilepsy may not have encountered. Thus, while a non-categorical approach may be helpful, cognizance of the particular psychosocial challenges arising from different chronic medical conditions is also important. This has implications on social work practice, particularly, group-based interventions. It influences decisions about who should be included in the intervention, and whether the content of the intervention should be modified to condition-specific needs. For instance, a non-categorical intervention approach could be adopted to help young people with illnesses that are characterized by unpredictability (e.g., epilepsy and asthma) to develop secondary control coping strategies. In contrast, a disease-specific approach would be more relevant if the aim is to educate and increase young people's knowledge about their medication

condition, such as disseminating information about treatment regimens, medication and its side-effects. In such instances, it would be necessary to tailor interventions to specific diseases.

The strength of a scoping review is in its comprehensiveness of evidence covered (Davis, Drey, & Gould, 2009), and this study provides a synthesis on what is known about young people's experiences of living with epilepsy. However, the results of this review should be interpreted in the context of this study's limitations. First, only English-language databases and journal articles were used and reviewed, respectively. Second, as this was a scoping review, the synthesis of qualitative findings was conducted without critical appraisal of study quality.

CONCLUSION

This review has attempted to provide a comprehensive and descriptive overview of the reported experiences of young people with epilepsy. While they experienced a myriad of feelings toward living with epilepsy, young people also reported support from various sources and their experiences were not always perceived to be negative. Such narratives not only challenge preconceived notions, which have been supported by quantitative research that living with epilepsy is often detrimental to the well-being of young people, but also provide others with the alternate view and understanding of their lives.

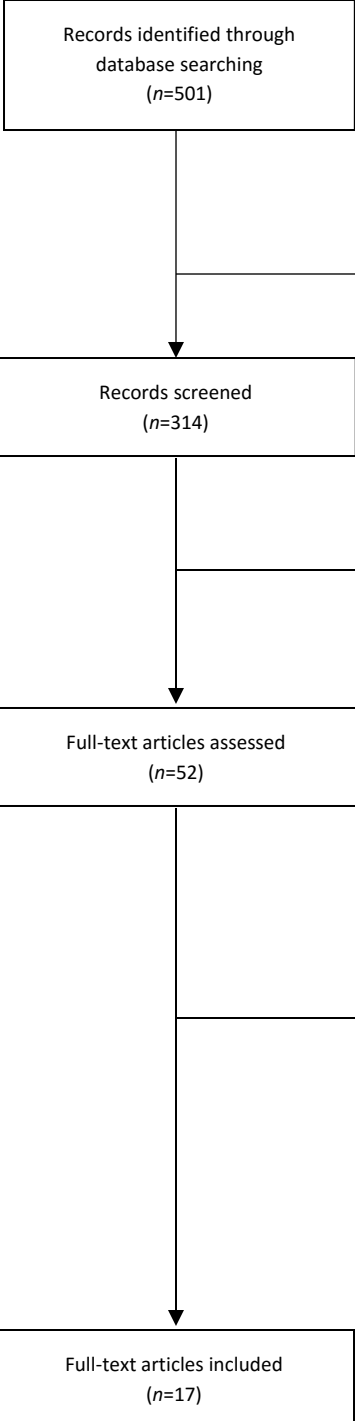
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Duplicates removed
(*n*=187)

- Records excluded
(*n*=262)
- Not in English language (*n*=38)
 - Conference abstracts, full-texts not available (*n*=6)
 - Not relevant (*n*=218)

- Records excluded
(*n*=35)
- Reviews (*n*=2)
 - Not relevant (*n*=2)
 - Evaluation of service (*n*=2)
 - Participants: Adults (*n*=12)
 - Participants: Children (*n*=6)
 - Participants: Mixed - Unable to extract YP's results (*n*=8)
 - Participants: YP - Did not use qualitative methods (data collection and analysis) (*n*=3)

Table 1. Summary of included studies by date of publication (n=17)

No.	Authors	Country	Topics	Population	Age	Sample size	Data collection method
1	Wilde and Haslam (1996) ^a	UK	Issues affecting young people with epilepsy	Mixed: YPE, YAE	13 to 25 years old	N=24 (9 males, 15 females)	Semi-structured interviews (SSI)
2	Galletti et al. (1998) ^a	Italy	Experiences of seizures and epilepsy in children and adolescents	YPE	6 to 18 years old	N=41	SSI
3	Beresford and Sloper (2003) ^a	UK	Experiences of chronically ill young people in communicating with health professionals	Young people with chronic illness (Cystic fibrosis, diabetes, epilepsy, juvenile chronic arthritis, or Duchenne muscular dystrophy)	10 to 16 years old	N=63 (27 males, 36 females) YPE – n=10	SSI and focus groups (FG)
4	Swarztrauber et al. (2003) ^a	U.S.	Patients' attitudes about the treatment of medically intractable epilepsy	Mixed: PWE and their families	YPE - 13 to 17 years old Adults with epilepsy and parents of YPE – age range not available	N=24 YPE - n=4 (2 males, 2 females) Parents – n=4 (3 mothers, 1 father) Adults with epilepsy – n=16 (10 males, 6 females)	FG
5	Eklund and Sivberg (2003) ^a	Sweden	Lived experience of young people with epilepsy and their coping skills	YPE	13 to 19 years old	N=13 (3 males, 10 females)	SSI
6	McEwan et al. (2004b) ^a	UK	Quality of Life in young people with epilepsy	YPE	12 to 18 years old	N=22 (6 males, 16 females)	FG
7	Elliott et al. (2005) ^a	Canada	Impact of epilepsy on their QOL	YPE	7 to 18 years old	N=49 (24 males, 25 females)	SSI
8	Lou Smith et al. (2006) ^b	Canada	Evaluation of memory outcome after epilepsy surgery. Qualitative phase: perception of young people's memory function	YPE	7 to 18 years old	N=42 (19 males, 23 females)	Objective assessments (scales), and SSI
9	McNelis et al. (2007) ^a	U.S.	Concerns and needs of children with epilepsy and their parents	Mixed: YPE and their parents	YPE - 7 to 15 years old Parents – age range not available	N=26 YPE – n=11 (6 males, 5 females) Parents – n=15 (12 mothers, 3 fathers)	FG

No.	Authors	Country	Topics	Population	Age	Sample size	Data collection method
10	Lewis and Parsons (2008) ^b	UK	Mainstream educational experiences of children with epilepsy	YPE	e-Survey – 3 to 23 years old (parental response on behalf of child) Interview - 6 to 17 years old	N=66 e-Survey – n=44 Interview – n=22 (9 males, 13 females)	e-Survey and SSI
11	Hum et al. (2010) ^a	Canada	Quality of life 2 years following epilepsy surgery.	Mixed: YPE, YAE	11 to 21 years old	N=27 (12 males, 15 females)	SSI
12	MacLeod (2009) ^{a#}	U.S.	Stigma in daily living	YPE	13 to 18 years old	N=4 (4 females)	SSI (multiple)
13	Mushi et al. (2011) ^a	sub-Saharan Africa	Social-cultural impact on PWE and their families and carers	Mixed: PWE and their families	15 to 60 years old	N=41 People with epilepsy – n=41 Carers – n=29	SSI
14	Carter et al. (2012) ^a	Kenya	Reasons for epilepsy treatment gap and to identify possible interventions.	Mixed: PWE and other stakeholders	YPE – 14 to 18 years old Other stakeholders - age range not available	N=110 YPE – n=8 (N.A.) Other stakeholders – n=102 (N.A.)	Interviews, FG, and participatory workshops
15	Ryan and Raisanen (2012) ^a	UK	Emotional experience of young people with epilepsy	Mixed: YPE, YAE	YPE – 16 to 19 years old Young adult – 20 to 28 years old	N=31 (14 males, 17 females) YPE – n=6 Young adult – n=25	SSI
16	Lewis and Noyes (2013) ^a	UK	Communication, information needs, and experiences of knowledge exchange in clinical settings during transition from children's to adult epilepsy services	Mixed: YPE and their parents	YPE - 13 to 19 years old Parents – age range not available	N=58 YPE – n=30 (N.A.) Parents – n=28 (N.A.)	Individual, small group interviews and FG; Documentation, archival records and physical artefacts were also reviewed
17	Manski and Dennis (2014) ^b	U.S.	Contraceptive experiences of female teens with epilepsy	YPE	Survey – 13 to 19 years old Focus group – 15 to 20 years old	N=140 Survey – n=114 Focus group – n=26 (26 females)	Online survey, and online focus groups

[#] Phd dissertation; ^a Qualitative study; ^b Mixed methods study; YPE - Young people with epilepsy; YAE – Young adults with epilepsy; PWE – People with epilepsy